

April 20, 2011

Attention: Tax Policy Committee

Thank you for the opportunity to speak with you today. Thank you for the dedication you all have as public servants and for trying to do what is right for MI constituents, even in hard and challenging times.

My name is Tiffiany, I live in Grand Ledge. I have a young adult daughter (Lindsey) that has disabilities. Her father (Rob) and I have always put Lindsey first; her needs; her education; her emotional well-being; therapeutic interventions; whatever it takes to help reach her full potential and to hopefully someday be independent, and successful.

It hasn't been easy, but I don't regret it, I would do it all again in a heartbeat, but things could have been so much easier on us as a family, and financially if we had had the support we needed. Lindsey has always seemed to fit into the "catch 22" area for services. Lindsey is developmentally disabled; she has a full scale IQ of 63. She is autistic (but high functioning), suffers from depression (but is fully stable).

Linz has always struggled with understanding money, social interactions and life situations. She often misunderstands situations with people that you and I take for granted because it comes so easily, like subtle sarcasm, someone trying to take advantage of her but using a nice tone in their voice, not always knowing yet when to ask questions because she doesn't understand. You and I can do these things very easily as adults, she can't yet. I remember the specialist at three years old explaining to us he wasn't sure if Linz would ever talk and knowing in my gut as her mother that somehow someday she would. I remember being so excited when at 5 when she began talking, at 9 when she made eye contact for the first time, at 13 when she actually made a tear in her eye for the very first time when she was upset.

Linz has had intervention services since she was 3 years old, but we knew at 2 that she needed help. The challenges have always been getting someone to listen and understand her; knowing what to put into place for her because of professional differences of opinions; having access to the right services; finding a provider for the services; and having the financial resources to provide for services that aren't provided by the system to give her the best shot at independence.

I feel fortunate that Rob and I realized when Linz was relatively young (10) that we had to figure out a way to pay for services that weren't being provided by the public agencies. But I also remember and still feel baffled that we couldn't gain access to services through the public mental health system because Linz is in the "catch 22" area. On paper her disabilities sound very significant, but she has a lot of strengths and resilience so she has rarely presented as "severe". We had private insurance as a family so she didn't qualify for Medicaid until turning 18, but private insurance doesn't cover therapeutic treatment options for the disabled because we don't have "Parity" in MI. We thought when she turned 18 things would get easier on us financially because she would qualify as an adult with disabilities so she would be entitled to SSI and Medicaid, but it hasn't got easier. Why, because Linz isn't seen as severe, like so many others. The "catch 22" areas are the individuals with "moderate and mild" disabilities.

I find it ironic that while she falls in the "catch 22" area, we have court orders that state she isn't able to live on her own, doctors' orders that she is required to have 24 hour supervision, she can't go to the college in MI designed for people with disabilities because her full scale IQ is 63 and your IQ can't be under 75 in order to

go there. Yes you heard me right there are individuals with disabilities that are considered too disabled to attend the college in MI that was designed to serve people with disabilities. I find it ironic that with all the barriers Linz still faces and we face as a family she is a "catch 22" and only considered mildly impaired and therefore can't be served by the public system.

Why because the "catch 22" individuals are served through the public system by general funds. But the general funds in the state haven't increased in a decade. The past three years the general funds have been cut. Why because we don't have a fair or equitable tax structure. That is causing the general fund to be less and less each year which leads to less and less of the population being served.

The public mental health system is obligated to serve the severe population of people with disabilities, whether it is a mental health or intellectual challenge under Medicaid. They also try to serve the less severe but again that comes out of general funds which is why I'm here today. The general funds haven't been increased in a decade and I believe for the past 3 years the general fund has been cut. So CMH's are left to make cuts to programs and serve less and less of the disabled population every year. The general fund has continued to decrease for a long time, over a decade now. I thought it was because of the recession but that's not it. It's because businesses are getting an 86% tax cut, or loophole to use, while individual constituents in the state are getting a 31% tax increase? Which boils down to \$7 billion collective coming into the general fund and \$35 billion never collected because of tax loopholes for businesses?

Governor Snyder stated that people with disabilities wouldn't lose services in his address. That's not reality. People with disabilities have lost services collectively for the last decade and they are getting ready to lose more. It's not only people with disabilities losing; communities across the state are losing. Meals on Wheels for example, most people think of Meals on Wheels and senior citizens having meals delivered to their homes at a very low cost. This is also a program that employees people with intellectual disabilities and has young adults come in and have on the job training and volunteer opportunities. So it isn't just impacting senior citizens getting meals, which is truly heartbreaking in and of itself. It is also impacting constituents in this state with disabilities having job opportunities.

Or how about the police departments that are getting ready to cut positions? Like locally in Lansing 78 sworn police officers will be cut, which will be neighborhood watch, school resource officers and the motorcycle officers just to name a few. Who do we think is going to respond to emergencies in a timely fashion when 36% of the police department is gone?

In the past I have testified in legislative hearings that I would support tax increases as a constituent if it would help with balancing the budget, thinking that it was because of the recession. But I didn't agree then and I don't agree now or support my taxes increasing year after year when businesses get loopholes and don't pay fair and equitable amounts. You can't balance the budget on the backs of families.

We need to invoke a fair, modern and stable tax structure in our state. Families and constituents across the state can't carry burden. Kids and families are being pushed into poverty. Kids and families are falling through the cracks and the cracks are getting bigger. The general fund continues to shrink year after year which leads to programs being cut that is designed to serve kids and families and our constituents.

If Rob and I weren't willing to take care of Linz, since she is an adult now she would be placed in a group home or residential setting because of the skills she has yet to learn to be able to live on her own. But since

we are her legal guardians and we have agreed to have her continue to live with us as an adult the majority of her services are paid for by us. I have a breakdown for you.

- \$120 every other week (9 months a year) and \$120 a week (3 months a year) for a caregiver while Rob and I are working, because a standing doctors order that she can't be left by herself. This will increase to \$125 a week in June permanently when she is done with school programming.
- \$50 a week for Equine Therapy. Studies show that people with Autism and horses have a very unique connection and learn from each other.
- \$75 a week for DBT therapy to continue to help her develop her communication skills.
- \$30 a week for gas for the caregiver to drive Linz to appointments.
- \$100 a month for co-pays for medications even with private insurance and Medicaid in place.

As you can see I'm not including just daily living costs, like food, clothes, rent, power, phone, spending money, or just typical primary caregiver physician co-pays. I'm including the things above and beyond what typical families and parents pay for their children. Plus, please consider this, Linz is 21 now. We are still paying for her care when most young adults are graduating from college and beginning to live on their own. Sometimes we only spend 800 a month because for some ironic reason more of the meds are covered. Or she doesn't see her therapist every week that month. Or her father or I take the day off for specialty appointments so we don't give the caregiver gas money.

Over the past decade Rob and I have spent \$96,000 on services for Linz. \$96,000 for services not covered by our private insurance and not covered by the public mental health system. Why, because she is in the "catch 22" area. She is considered mildly impaired, and because the general fund continues to shrink and Community Health continues to have cuts because we don't have a fair and equitable tax structure.

We could have invested that into our retirement, of which we currently have none. We could have thousands in savings, of which we currently have none. We could have bought a house instead of renting all these years. We could have taken family vacations; we haven't taken a real family vacation since Linz was 8 years old. Or Rob could be driving a car that's not nearly 20 years old (93 toyota) with over 300,000 miles on it.

What we have spent on Linz over the past ten years, is spent by the state in 1 year on 1 individual who is considered "severe" in residential. Professionals have told us time and time again if we hadn't spent the money on all of the services that she has got, Linz would be in the "severe" range. Which supports what all the research shows, early intervention is crucial to have longstanding success. If she was in residential that would be paid for by the state and it would end up as one more thing on the backs of families to pay for.

I realized a long time ago that we could fight the system. We could hire an attorney, go to court and make them provide services, but we wouldn't be able to pay for services and pay for an attorney at the same time. So Linz would lose valuable time in her development. Or I could learn about the problems in the system and figure out a way to help make it a better one. It's not about just making it better for Linz; it's about making it better for everyone with disabilities.

I started advocating for individuals with disabilities, when Linz was 10 years old. When I truly started to see the disparities, inequality, and overwhelming barriers that individuals with disabilities faced. I wanted to make a difference not just for Linz but for all individuals. I don't want handouts, and I don't want sympathy.

I want full understanding, acceptance and accountability. I want our public servants to do the right thing. I want individuals like Linz to be embraced for the amazing individuals that they are. For individuals like Linz, to have equality, access, services and supports to be able to become independent; successful; and contributing members of society. I want the needs of all individuals with disabilities to be known and supported. But most importantly I want our state to invoke a fair and equitable tax structure because the one we have now is nowhere close to fair or equitable.

As you know, Governor Snyder has stated that no services will be cut for the disabled, but that isn't reality if the general funds are cut once again. The majority of the disabled population will be impacted just like they were last year, the year before that, and for the past decade. It is when we only get a portion of the facts that detrimental decisions continue to be made. Then we continue the cycle of not serving the ones that need it. We are each responsible as individuals if we continue to overlook the needs of the disabled as a whole. We can no longer serve a "snip it" of the population. All of our residents deserve better than that. On top of that the disabled population in our state, that is only a "snip it" of the population that is impacted by the current tax structure. But I can only testify as an individual of what I understand and how my family is detrimentally impacted. The general fund, business tax credits, and Parity seem to be the answer. Businesses are getting an 86% tax credit while individuals are getting a 31% increase in taxes is wrong. That leads to only \$7 Billion coming into the general fund, while \$35 billion is not because of loopholes for businesses. We need a fair, stable and modern tax structure implemented. As a constituent it seems like you all are the ones in charge of doing that. If I'm coming to the wrong place tell me where do I need to go. Who in our legislature needs to hear and understand what these loopholes are costing families?

I need my officials to understand what is going on. I need you to take a stand and take charge of the inequalities that individuals with disabilities and families face in MI. I need Governor Snyder's message to people and to our officials to be accurate, "no cuts to individuals with disabilities". Thank you for your time and for your dedication.

Sincerely,



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